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6. ANNB screening: supporting women with learning disabilities (<https://www.gov.uk/government/publications/annb-screening-supporting-women-with-learning-disabilities>)

1. Public Health

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Guidance

Antenatal and newborn screening: supporting women with learning disabilities

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This publication is available at <https://www.gov.uk/government/publications/annb-screening-supporting-women-with-learning-disabilities/antenatal-and-newborn-screening-supporting-women-with-learning-disabilities>

The screening tests offered during pregnancy are:

- Down's syndrome, Edward's syndrome, Patau's syndrome and the 20-week scan (<https://www.gov.uk/guidance/fetal-anomaly-screening-programme-overview>)
- infectious diseases in pregnancy screening (<https://www.gov.uk/guidance/infectious-diseases-in-pregnancy-screening-programme-overview>)
- sickle cell and thalassaemia screening (<https://www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview>)

The screening tests offered for newborn babies are:

- newborn and infant physical examination screening (<https://www.gov.uk/guidance/newborn-and-infant-physical-examination-screening-programme-overview>)
- newborn blood spot screening (<https://www.gov.uk/guidance/newborn-blood-spot-screening-programme-overview>)
- newborn hearing screening (<https://www.gov.uk/guidance/newborn-hearing-screening-programme-overview>)

We know screening inequalities (<https://phescreening.blog.gov.uk/2017/09/12/screening-inequalities-and-what-were-doing-about-them/>) exist among people with learning disabilities (<https://www.nhs.uk/conditions/learning-disabilities/>) and they are less likely to access screening.

We also know people with learning disabilities receive a poorer standard of care, and die earlier (<https://www.england.nhs.uk/publication/leder-action-from-learning/>), than people without learning disabilities.

There is also evidence to suggest women with learning disabilities struggle to understand information ([https://www.midwiferyjournal.com/article/S0266-6138\(15\)00259-4/abstract](https://www.midwiferyjournal.com/article/S0266-6138(15)00259-4/abstract)) (which is often written) given to them during pregnancy.

The Public Health England (PHE) screening inequalities strategy (<https://phescreening.blog.gov.uk/2018/05/24/mind-the-gap-phe-screenings-inequalities-strategy-launches-today/>) explains how we are working with others to remove gaps in services that prevent everyone being able to access screening.

Health professionals should use this information to help women or parents with learning disabilities better understand and access antenatal and newborn (ANNB) screening.

1. Informed choice

Women or parents should be helped to make an informed choice (<https://phescreening.blog.gov.uk/2019/08/07/helping-health-professionals-support-personal-informed-choice-in-screening/>) about the antenatal and newborn (ANNB) screening tests they are offered during pregnancy or after the baby is born. In particular, some screening tests in pregnancy (<https://www.nhs.uk/conditions/pregnancy-and-baby/screening-tests-in-pregnancy/>) can lead to personal decisions about whether or not to continue a pregnancy. Health professionals should explain these as clearly as possible to women with learning disabilities.

2. Recommended tests

Some ANNB screening tests are recommended by the NHS. These are:

- eye screening if a woman has pre-existing diabetes (not gestational diabetes)
- infectious diseases in pregnancy screening

- newborn and infant physical examination screening
- newborn blood spot screening
- newborn hearing screening

However, it should always be an individual woman's or parent's choice whether or not to have screening.

3. Barriers to screening

Women or parents with learning disabilities may find making a choice about screening challenging. This could be because of:

- practical barriers, including mobility issues and difficulty using appointment systems
- a lack of family or carers to support attendance at screening and local support services
- negative attitudes towards screening among people with learning disabilities
- a lack of knowledge about screening among people with learning disabilities
- communication barriers between women or parents and health professionals
- a lack of knowledge among health professionals of the needs of people with learning disabilities
- a lack of awareness among screening staff about easy guides or other resources to support people with learning disabilities

4. Support during screening

4.1 Before the screening appointment

Before the appointment you should:

- find out if the hospital has a learning disability liaison nurse, or other health professional involved in the woman's care, who can offer support during the screening appointment
- consider how the individual likes information to be presented and tailor it accordingly – for example, by using pictures, simple words, symbols, signing or film to explain screening
- be aware of any jargon or medical terminology you may be using and try to explain things in a simpler way
- find out if the individual has an up-to-date communication or hospital passport (<https://www.mencap.org.uk/advice-and-support/health/health-guides>) which can help to make them feel comfortable
- discuss any adjustments or communication needs an individual might need with them ahead of any appointments
- think about the logistics for the appointment, such as checking how they are going to get there
- appropriately share information and ensure a coordinated support package is in place so the relevant health professionals can work together – effective handovers can improve accessibility and understanding
- consider showing the woman what will happen during the appointment by showing her the rooms and explaining what the equipment does, including any noises it makes – use photos if a visit is not possible
- give the woman the chance to meet the members of the healthcare team most likely to provide care
- let the woman know she can have somebody present during appointments and help arrange this if necessary – engage with the woman's family or friends, if the woman agrees
- assess the individual's capacity and any safeguarding issues that need to be considered
- check if the appointment will take place in a quiet environment and consider a home appointment if necessary

4.2 During the screening appointment

There are lots of specific things health professionals can do to make screening appointments better for women or parents with learning disabilities. They can:

- use simple language, avoiding long words and long sentences
- speak slowly and clearly, and stop to check understanding at regular points
- show the woman or parents the relevant 'Screening tests for you and your baby' easy guide leaflet or video and discuss it with them
- always talk directly to the woman or parents, not their carer or supporting professional
- follow the woman's or parent's lead and go at their pace
- be aware that women or parents with learning disabilities are more likely to have hearing loss, so do check they can hear you

These are suggestions and will not be appropriate in all cases. Find out how best to support each individual.

5. Resources

Clear, concise, easy to understand information helps support communication and understanding for people with learning disabilities.

Health services should be aware it is a legal duty (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty>) to make reasonable adjustments (<https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty#what-we-mean-by-reasonable-adjustments>) for people with learning disabilities.

5.1 Easy read information

The NHS England 'Better Births' report (<https://www.england.nhs.uk/publication/better-births-improving-outcomes-of-maternity-services-in-england-a-five-year-forward-view-for-maternity-care/>) says people with learning disabilities benefit from:

- being able to access information in easy read format
- healthcare professionals taking time to ensure that they understand what is happening and the choices they can make

PHE has produced 'Screening tests for you and your baby' easy guides (<https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides>). These 8 easy read guides explain the screening tests offered during and after pregnancy for people with learning disabilities.

Health professionals should download and print off copies to use when explaining ANNB screening tests to people with learning disabilities. If possible, you should print them single sided and in colour to improve accessibility for people with learning disabilities.

5.2 Videos

Short films such as the 'Screening tests for you and your baby' video can be used alongside easy read guides and letters to help understanding. These videos can be useful for health professionals to watch with women or parents while talking about screening.

You could search online to find video content. Do make sure you have watched videos to the end to check they are accurate, appropriate and helpful to people with learning disabilities before using them.

Also consider:

- obtaining the opinion of an independent advocate if professionals, families and carers cannot or do not agree on what is in the woman's or parents' best interest
- reviewing the woman's past screening, family and obstetric history
- the woman's or parents' beliefs and wishes, which could influence a best interest decision for them

Also consider if the woman has attended screening regularly before, which implies she once felt it was important. This knowledge could influence others when making a best interest decision for her.

8. Further support and information

Find out what support is available for health professionals and people with learning disabilities in your area. There may be a person or team that can offer additional help, for example, a local learning disability team or primary care liaison team.

PHE screening blog articles (<https://phescreening.blog.gov.uk/>) provide up to date news including information about breast screening and inequalities. You can register to receive updates (<https://phescreening.blog.gov.uk/subscribe/>) direct to your inbox, so there's no need to keep checking for new blogs. PHE also has a dedicated Screening Twitter account (https://twitter.com/PHE_Screening).

9. Accessibility in your workplace

You can improve accessibility in your workplace by:

- sharing the screening tests for you and your baby easy guides (<https://www.gov.uk/government/publications/screening-tests-for-you-and-your-baby-easy-guides>) – consider printing them and leaving them in waiting rooms
- raising the issue of information for pregnant women with learning disabilities in meetings and staff communications, such as on the intranet
- turning these tips into a poster or screen saver
- sharing your experience of using the easy guides and suggestions for improving information for people with learning disabilities via the PHE Screening helpdesk (<https://phescreening.blog.gov.uk/helpdesk/>)

Contact the PHE Screening helpdesk (<https://phescreening.blog.gov.uk/helpdesk/>) with any queries about this publication, making sure you include its full title.

Screening tests for you and your baby | NHS



5.3 Other resources

Other resources for supporting people with learning disabilities are available from:

- NHS England (<https://www.england.nhs.uk/learning-disabilities/about/resources/>)
- Mencap (<https://www.mencap.org.uk/about-us/what-we-think/health-what-we-think>)

6. Standards

Other useful sources of information include the Accessible Information Standard (<https://www.england.nhs.uk/ourwork/accessibleinfo/>) and the Equality Act 2010 (<https://www.gov.uk/guidance/equality-act-2010-guidance>), which legally protects people from discrimination.

You can also learn more about reasonable adjustments (<https://www.equalityhumanrights.com/en/advice-and-guidance/what-are-reasonable-adjustments>) from the Equality and Human Rights Commission.

7. Making a best interest decision

The decision whether to have screening or not can only be made by the invited woman or parents, or through a best interest decision.

If women or parents have not understood enough to make up their own minds about ANNB screening, then people involved in their care need to make a best interest decision for them. This may include screening staff, family members, carers or her GP. Include the women or parents in discussions as much as possible.

The Mental Capacity Act (<http://www.legislation.gov.uk/ukpga/2005/9/contents>) sets out the law regarding capacity and consent and the Code of Practice (<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>) provides guidance through the correct process in cases where there are concerns that an individual may not have the capacity to make an informed decision.